Definitions of:

# PATHOLOGY IMPAIRMENT FUNCTIONAL LIMITATION DISABILITY

Implications for:

PRACTICE RESEARCH

PROGRAM & POLICY DEVELOPMENT SERVICE DELIVERY

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# PATHOLOGY, IMPAIRMENT, FUNCTIONAL LIMITATION AND DISABILITY-IMPLICATIONS FOR PRACTICE, RESEARCH, PROGRAM AND POLICY DEVELOPMENT AND SERVICE DELIVERY

Report of First Mary E. Switzer Memorial Seminar

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#### FOREWORD AND ACKNOWLEDGEMENTS

The seminar which produced this report was made possible by an appropriation from the Mary E. Switzer Memorial Fund. This fund was raised in a national campaign, headed by Olive Banister, to establish a memorial to Mary E. Switzer, to whom a tribute is paid in this report. The Board of Directors of the Association decided to use approximately one-half of the funds to support seminars to discuss topics vital to the future of rehabilitation, of which this is the first. The other half of the fund will be used to support scholarships and fellowships to individuals to enable them to explore areas of concern to the rehabilitation movement.

The individuals invited to participate in the seminars were designated as "Mary E. Switzer Fellows." Their cooperation, of course, was essential to the success of the enterprise. Special thanks go to four of the fellows who prepared papers which were the major resources for use in the seminar and upon which this report is based. They are Saad Nagi, Barry Craig, Joe Moriarty and Lawrence Haber.

Finally, appreciation is expressed to the thousands of individuals and organizations who contributed to the Mary E. Switzer Memorial Fund. It is hoped that the use being made of their contributions will justify their support.

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#### MARY E. SWITZER-A TRIBUTE

For seventeen years, Mary E. Switzer presided with grace and distinction over the federal vocational rehabilitation program in this country. For four additional years, she headed the Social and Rehabilitation Service, of which the rehabilitation agency was a part. The Mary E. Switzer Memorial was established by the National Rehabilitation Association to honor her and perpetuate her memory.

Mary E. Switzer was a woman of vision, endowed with exceptional ability, courage, strength of character and deep compassion, coupled with a grace and charm that endeared her to all who worked with her. As a dedicated woman and public servant, she never lost sight of her goal of helping disabled and otherwise disadvantaged people live with dignity, self respect and honor.

Mary E. Switzer fervently believed that these goals could best be met by a true partnership of the public and private sectors and tirelessly devoted her energy to achieving this by bringing together the best of both groups to harmoniously develop services that would complement but not compete each with the other. Mary E. Switzer inspired all who came into her orbit to push for new horizons and new hopes for disabled individuals.

It is especially fitting that the first Mary E. Switzer Seminar should be directed toward clarifying thinking on the basic concepts on which an enduring rehabilitation effort must be based. How Mary would have enjoyed the discussions that produced this report! Memories of her charm and vitality and her demand for relevance in conference were humbling forces to all who participated.

**OLIVE BANISTER** 

#### INTRODUCTION<sup>1</sup>

The purpose of the Seminar was to discuss and possibly arrive at consensus concerning the meanings of "pathology", "impairment", "functional limitation", and "disability", so that these terms and concepts can become more efficiently useful in rehabilitation research, policy, programs, and practice. This type of activity is of prime importance at this time in rehabilitation work because of the apparent confusions among the helping disciplines and the public concerning the definitions and assumptions on which we base our values, goals, procedures, and pursuit of new knowledge.

For the past 50 years thousands of professional people have helped disabled people to build a new social and working life. They and their observers have assumed that what they were doing was desirable and "right" and properly oriented, and probably efficient and effective. In the Judeo-Christian ethic, to help others has always been a respected and honorable activity. However, in these later years we and our sponsors have questioned our methods and goals. Certainly, we have been doubtful and sometimes confused about our languages and terms. When pressed, we have not always been able to agree on the descriptions of the concepts and theories that have guided us. We have lacked the means to measure and to demonstrate the efficacy of our procedures. This has not only reduced the social impact that rehabilitation might have had, it has severely impeded the productivity of the relatively well financed programs of research that we have had since 1954.

Many of us have found science and science methodology to be helpful in situations such as we find ourselves, where we must test our myths, assumptions, prejudices, and fears. But science and its methods require clear concepts, language that can communicate accurately, measurement potential, a level of imagination that can insure good research design, and the vision to see ahead to utilization and application. Science tests assumptions and hypotheses. It is useful in our efforts to control and predict movement within a discipline. But to judge if movement is taking place, we must have points of reference; and currently, in our work we have not always fixed the reference points or developed the desirable precision. One of the basic goals of this seminar was to clear away some of the semantic smog and to promote exactness of concepts and language in our work.

Once the concepts and terms of rehabilitation have been etched and accepted, we will have created a much greater potential for development and communication. But we will not have solved all the problems related to enlisting the resources and assets of scientific approach. Especially in our work we must deal with the reality of the great complexity of human beings and the environments in which they live, as these two elements are merged in functioning in a moving universe. Science, as we know it and as we have tried to apply it to social and biological phenomena, is limited and restrictive. If we are to avoid the hazard of having science become the new medieval straitjacket, the concepts and languages that we use must remain dynamic, always subject to revision, and, we fear, complex. What was adequate or at least revealing for physics and chemistry will not necessarily suffice in discovering and explaining what we so much need to know about basic biological and social interaction.

To deal with the phenomenon of human beings functioning in varying environments, we will have to think beyond such limiting terms and concepts as "medical model", "social model", or "statistical model"; in our work we must contemplate the "human model". That suggests involvement of all the disciplines that have anything to contribute with reference to human

<sup>&</sup>lt;sup>1</sup>This Introduction is based on a statement made by C. Esco Obermann opening the Seminar.

functioning or with reference to survival and ecological demand. Central to all our values and experience is the concept of the uniqueness of each individual—one who is not to be depersonalized and lost in such terms as "the disabled", "the handicapped", or "the impaired".

We do not see our task as a simple one or one that will be soon finished. We are fortunate to have the resources of the Mary E. Switzer Memorial Fund to help in this important undertaking. If through a series of seminars such as the one reported on here we can begin to clarify the concepts and languages of rehabilitation, we will have accomplished something that far transcends our own work; we will have made a significant contribution to the management of a whole range of social and biological problems that beset our times.

In this report, the readers have the essence of the papers and discussions of the First Mary E. Switzer Memorial Seminar. It is for the reader to judge whether it makes an important contribution to the goals we have discussed. If it proves to be a stimulant of more thought, more discussion and more research, those of us who have participated in the seminar will be amply rewarded.

#### Chapter One

### DEFINITIONS OF PATHOLOGY, IMPAIRMENT, FUNCTIONAL LIMITATIONS AND DISABILITY<sup>1</sup>

As Dr. Obermann has stated in his introduction, we expect to begin with an exploration of the concepts of pathology, impairment, functional limitations and disability, four entities an understanding of which is essential as a basis for clarifying our concepts of rehabilitation. Whether the words we use to label these concepts are the words finally chosen for this purpose is not as important as understanding the concepts, but the words we use can be defended on the basis of consistency in previous use.

#### CONCEPTUAL DEFINITIONS

Definitions to be most useful must be both conceptual and operational. We shall begin, of course, with the conceptual.

#### **Pathology**

The state of active *pathology* is associated with mobilization of defenses and coping mechanisms, and may be the result of infection, metabolic imbalances, degenerative disease processes, trauma, or other etiology. Such a condition involves two conceptually distinct phenomena: (a) the interruption of normal processes, and (b) the simultaneous efforts of the organism to restore a normal state of existence. Pathology then is not merely the surrender to an abnormal state of affairs but also the fight for health. In modern health practice the organism is aided in its fight by surgical elimination of defective parts, administration of medications, or other types of therapy intended to help regain equilibrium. Such means of intervention may become necessary over a long period or indefinitely, as in the case of some types of chronic diseases.

#### **Impairment**

The concept *impairment* indicates a physiological, anatomical, or mental loss or other abnormality, or both. It is obvious that by definition a pathological process also involves physiological, anatomical, and/or mental deviations, that is, an impairment. However, distinction between the two phenomena becomes meaningful when impairments not involving active pathology are considered. Examples of such impairments can be found in abnormalities and residual losses remaining after the active stage of pathology has been arrested or eliminated, in non-pathological congenital deformities, and also in conditions resulting from the disuse of muscles or organs for extended periods of time. Therefore, it can be said that every pathology involves an impairment but not every impairment involves pathology. Impairments vary along a number of dimensions such as the nature and degree of limitations they impose upon the organism's capacities and level of functioning, the degree of visibility and disfigurement, the state of underlying pathology, if any, and the prognosis and prospects for recovery or stabilization. These and other characteristics determine the ways impairments influence the nature and degree of disability.

<sup>&</sup>lt;sup>1</sup>Based upon paper of Saad Z. Nagi, "Disability Concepts and Prevalence."

#### **Functional Limitations**

The most direct way impairments contribute to disability is through the functional limitations they effect. This brings to question the level of organization of the organism at which the limitations are manifested. Altered structure or function of many tissues can exist without any limitations imposed on the functioning of the organism as a whole. A significant number of muscle fibers must become denervated before discernible weakness occurs. Much alteration in the walls of blood vessels can take place before appreciable changes in the flow within these vessels would ensue. Virtually an infinite number of similar examples could be enumerated. One could speak of limitations in function at the levels of molecules, cells, tissues, organs, regions, systems, or the organism as a whole. While it is true that limitations at a lower level of organization may not be reflected in higher levels, the reverse is not true. An individual who is unable to reach overhead because of tightness in the shoulder can be expected also to have abnormalities at the levels of tissues and cells that make up the shoulder. It is important to note that limitations in functions at higher levels of organization may result from differing impairments and functional limitations at lower levels of organization. For example, inability to lift a heavy weight may be related to mechanical problems in the lumbosacral region, or it may be the result of diminished cardiac output or pulmonary ventilation.

#### Disability

Moving beyond the level of organismic functioning to social functioning, disability can be defined as a form of inability or limitation in performing roles and tasks expected of an individual within a social environment. These tasks and roles are organized in spheres of life activities involved in self-care, education, family relations, other interpersonal relations, recreation, economic life, or employment and vocational concerns. Although short-term sickness may be disabling for a brief duration, the term disability is usually applied to inabilities of long or continued duration. It may be associated with the presence of active pathology, or with remaining impairments after pathology has been controlled or eliminated as in the case of healed amputations or residual polio paralysis. It should be apparent that not every impairment results in disability, and that similar patterns of disability may result from different types of impairments and limitations in functioning on the organismic level. Furthermore, identical types of impairments and functional limitations with similar degrees of severity may result in different patterns of disability, depending upon the reactions of the disabled and the social definition of the situation. This indicates that the etiology of disability, like most complex phenomena, can be explained only through multiple causal models and therefore can be identified and measured only by multiple indicators.

#### Mental Conditions

This relationship among these concepts is more clearly applicable to physical than to mental conditions. Many contend that models used in defining and identifying structural and physiological pathology and impairments are not suited to emotional and intellectual problems. Proponents of this position also maintain that the etiology and definitions of the latter problems are more socially grounded. While examples can be found to fit the conceptual entities in the present scheme, three major difficulties are encountered in applying it to emotional and intellectual conditions. The *first* is that, except for certain types of cases including organic conditions, the indicators of pathology, impairment, functional limitations, and disability are not empirically separable. They are all inferred

from the same behavioral manifestations. The *second* difficulty lies in the absence of signs and laboratory findings identifying many types of emotional problems, with the consequent dependence upon symptoms as expressed by the patient. This relates to the *third* difficulty, which is the absence of well established and widely observed criteria for consistent classification even on the basis of symptoms. The status of knowledge about mental disorders has led some researchers and administrators to concentrate on measuring limitations and disabilities and bypassing the identification of pathologies and impairments as an initial step. While less appropriate for treatment and clinical management of patients, this approach better serves the purpose of evaluating eligibility for disability related benefits and assistance. It is also entirely consistent with the thesis embodied in the conceptual distinctions presented above—that disability is manifested at the social rather than the organismic level of activities, that different types of impairments may result in the same pattern of disability, and conversely, that similar impairments may result in differing patterns of disability.

#### **Further Clarification**

Three issues deserve further clarification: (a) the use of the term "handicap"; (b) the applicability of the term disability to limitations in role performance that stem from congenital and early childhood pathologies and impairments; and (c) differences between disabilities and other forms of inabilities such as technological obsolescence. The term "handicap" has been widely used in the field of rehabilitation in the way we are using the term disability. The term handicap emerged during the early developments of rehabilitation counseling in an attempt to distinguish "medical" entities which constitute the professional domain of physicians from the "non-medical" entities which were to become the domain of rehabilitation. The AMA's Committee on Medical Rating of Physical Impairment, however, made it clear that disability is not a medical phenomenon and therefore is not an exclusive area of physicians' competence and practice. The term handicap has never been operationally defined in a way that allows an assessment of what specifically it designates. Until such definitions are available it will be difficult to say whether what it designates is an exact equivalent of what is here labeled disability. The use of the word handicap in so many fields that have no bearing on impairments or rehabilitation can be used as argument for dropping the use of this word as a label for functional limitation.

Because the word *disability* implies a change from prior higher levels of functioning, its applicability to inabilities stemming from congenital and early childhood impairments is questioned. In this respect, distinctions have been made between congenital and "adventitious" inabilities—the latter being *disability* in the strict sense of the word. Perhaps a conceptual scheme should begin with the more fundamental concepts ability-inability where disability becomes one form of inability. The term disability, however, has become accepted in designating limitations arising from congenital conditions.

#### Inability

Two types of change can lead to the precipitation of inability. The first is an individual change in characteristics intrinsic to the person. Such change can be of anatomical, physiological, mental and/or psychological nature. It also can be in such characteristics as age that are socially important to the performance of certain roles. The second is environmental change that follows alterations in the structure and definitions of roles and tasks or their discontinuation. For example, an individual may become unable to fulfill his family roles because of changes in the family rather than in

himself. Applied to vocational activities it can be said that inability to perform the functions of a job can be the result of a modification to include some unfamiliar or more difficult tasks, or the elimination of the original functions entirely. Technological unemployment constitutes a form of inability that results from change in the vocational environment.

Combining the two types of change would indicate that inability can occur as a result of: (1) individual change, (2) individual and environmental change, and (3) environmental change. Although analytical distinctions can be made between individual and environmental change, in most cases the relationships between the two are close and dynamic. There is considerable evidence, for example, that environmental changes which interfere with an individual's adjustment in his life activities also affect his health. By the same token, many individual changes engender biases in employers and others significant in one's environment.

#### **OPERATIONAL DEFINITIONS**

Distinctions should be made between *constitutive* and *operational* definitions of disability. A constitutive definition is one that conveys the meaning of a concept in terms of other concepts, as in defining disability in terms of inability to engage in gainful activity because of the presence of an impairment. Such a definition explains disability by relating it to other concepts, but does not specify the steps by which the concept is to be identified and measured. A system built exclusively around constitutive definitions is bound to be circular.

#### Indicators

To operationalize concepts is to identify them through indicators and to define these indicators in terms of measures and criteria for these measures. Defining intelligence by what I.Q. scales measure, and poverty by a certain point on the continuum of family income, exemplifies operational definitions. On developing operational definitions it is important to distinguish between concepts of attributes and properties and relational concepts. The first type of concepts includes those concerning the individual properties of a person or other objects of description. Height, weight, and intelligence are examples of such concepts. Indicators for these concepts can all be found within the characteristics of individuals. In contrast, the indicators of a relational concept cannot be all accounted for within individual units of analysis. Some indicators are to be found in related segments of the situation. To illustrate these distinctions, and to bring them to bear on the subject matter of this report, we may apply them to the concepts of impairment and disability. Physical impairment is a concept of properties and attributes in that all of its indicators can be found in the individual. We need not go beyond examining the individual in question in order to identify the presence and extent of physiological and anatomical losses or disorders. On the other hand, the concept of disability is relational in the sense that its indicators are not only to be found in the person pronounced disabled but in other entities such as the requirements of roles to be performed, the attitudes of others, and a host of additional situational factors. For example, while some of the indicators of vocational abilities-inabilities are intrinsic to the afflicted such as: (1) the physical and mental capacities and limitations of the individual, (2) the vocational skills possessed by the individual, and (3) the individual's motivation toward work; other indicators are of a situational nature such as: (4) the physical and mental requirements of the work, (5) the vocational skills required by the work, and (6) the environmental factors which make employment accessible

or inaccessible. To account for the various types and degrees of vocational inability, indicators for these various dimensions must be included. As pointed out earlier, disability as a concept generally excludes inabilities that do not involve limitations in the physical and/or mental capacities.

#### **Problems Encountered**

Several problems characterize operational definitions and measures of disability in studies and programs. The *first* most common difficulty stems from the confusion between disability and impairment. This is most characteristic of Workmen's Compensation and Veterans' Administration programs which combine aspects of indemnification of impairments with compensation for income loss due to disability. Benefits are often based on schedules specifying rates of compensation for anatomical losses, such as a finger, a hand, an arm, or an eye. These schedules are concerned almost exclusively with impairments, regardless of their effects upon earnings. The problem lies primarily in the third requirement, and, in this respect, medical factors are just as problematic as those of a non-medical nature.

A third factor that reinforces the heavy reliance upon impairments as indicators of disability is the interpretation of the term cause in the various statutes. Non-engagement in gainful activity may result from disability, unemployment because of labor market conditions, or mere idleness. In order to draw the boundaries, most statutes state in one form or another that for non-engagement in gainful activity to be considered as an indication of disability it must have occurred because of the presence of impairments. Often the term because is interpreted to mean that impairment is a necessary and sufficient cause for disability, and that in this sense the two are equitable. Differences between impairment and disability in definitions and indicators negate such interpretation except in cases where impairments are so extremely limiting as to clearly indicate disability. However, in most cases, including those allowed benefits under a variety of programs, impairments are actually a contributing cause. Even in the state-federal vocational program, in which law and regulation clearly indicate that impairment must result in substantial handicap (disability) for an individual to be eligible for service, impairment, unconsciously, often is equated with disability. For instance, although medical authorities have long stated that a below knees amputee can, so far as his impairment is concerned, perform practically any kind of work without limitation, whoever heard of a rehab agency rejecting an amputee on the basis that he was not disabled?

Differences in criteria constitute a *fourth* influence on operational definitions. Agencies may agree on factors that contribute to disability but use different cutting points on some or all of the factors when distinguishing the disabled from the nondisabled. For example, in most private insurance, at least for an initial period, an individual is considered disabled if he cannot perform work similar to his own job. In contrast, under social security programs, an individual must not be able to engage in any substantial gainful activity in order to qualify for disability benefits.

Some agencies rely primarily on the judgments of professional groups or teams with little or no indicators or criteria to guide decisions. In effect, the operational definition of disability in such agencies is that it is what one or a group of professionals say it is. Welfare agencies lean more in this direction in evaluating applicants for Aid for the Permanently and Totally Disabled (APTD). The general acceptance of a physician's statement for the purposes of Temporary Disability Insurance (TDI) provides another example of this approach. Often, extraneous factors such as individual differences among professionals and variations in therapist-patient relationships strongly influence

this form of operational definition. In the vocational rehabilitation program, medical reports seek to relate impairment to functional limitations with uneven results. It is generally accepted that the determination of disability is an agency function, and the decision is made by agency professionals, although frequently without the availability of objective criteria.

Abstract concepts in studies and statutes usually evoke less controversy and disagreement than the indicators and measures used to operationalize them. In research, the relationship between concepts and measures calls into question the scientific issues of reliability and validity. In addition, the important legal and moral question of equity is often raised concerning measures used in establishing eligibility for benefits and services in the various disability programs. In specifying operational definitions of concepts embodied in the statutes, administrative agencies exercise what actually amounts to legislative powers. Serious challenge to such definitions and measures employed by service agencies usually comes from the courts-a condition that makes for great sensitivity on the part of these agencies to certain court decisions. In general, a court decision reversing an agency's determination may fall in one of two categories: (a) accepting the operational definitions but questioning their application to the case in question—the question here relates to the decisions reached but not the criteria for decision making, or (b) questioning the operational definitions and measures themselves as resulting from faulty reasoning and/or invalid evidence when derived from the abstract concepts in the laws. While only a small proportion of cases reaches the courts, much significance is attached to decisions rendered on the latter basis because of the doubt they cast on the criteria and related procedures employed in decision making. Court reversals that fall in this category often cause pervasive changes in agencies' operations.

#### ON CLASSIFICATION

Not all differences among definitions of disability in studies and programs represent differing conceptions or problems in operationalization. At times, programs are concerned about differing types of disability. For example, Aid to the Blind is for those whose disabilities involve visual impairments, Workers' Compensation is for disabilities induced by work-connected impairments, and disability insurance programs under Social Security are for disabilities that continue for a certain minimum of time. To classify is to differentiate among the sub-categories of a general class. The process is essential in developing scientific explanations and in program planning. Problems arise when the blanket term *disability* is used to refer to all sub-categories without further specifications, as is true of the state-federal vocational rehabilitation program. Previously, we have identified disability as a category of inabilities, and the problem here is one of distinguishing the different types of disability.

Any attribute of an entity can be used in classifying that entity. In this sense, disability can almost be classified in an infinite number of ways. It is important to note, however, that the significance of a classification scheme stems from its theoretical or program relevance. For example, a disability classification appropriate for intervention programs could be based upon variability of the underlying pathologies and impairments and their prognoses. On the other hand, a classification based on the severity of restrictions in vocational activities is more fundamental for disability benefit and vocational rehabilitation programs. The literature abounds with attempts to classify disabilities and the disabled. Most commonly, they are classified according to impairments; to the spheres of life activities affected (e.g., vocational activities, activities of daily living, etc.);

work-connectedness, age at onset, and duration. Aside from failure to observe systematic approaches in devising classification schemes, the most common problem that plagues the literature on disability is the indiscriminate use of such schemes regardless of their appropriateness to the context.

Distinctions should be made between artificial and natural classifications. The first is based on an arbitrary selection of variables and points of grouping. Natural classifications are based upon theoretically relevant variables and criteria for distinguishing categories. To illustrate, logical and theoretical questions might be raised regarding a classification of disabilities based upon impairments—a classification that underlies the creation of specific programs and other privileges for those with visual impairments. Similar questions might be raised concerning criteria for grouping disabilities on the basis of duration. In other words, why a six-month duration for temporary disability insurance programs under Social Security, or a six-month waiting period under temporary disability insurance? Obviously, one program is oriented toward disabilities of long duration while the other is intended for shorter duration. However, the question still remains as to whether six months represents the most significant point of differentiation. The question can be resolved only by data that would show the distribution of disabilities on duration.

#### **National Survey**

For use in a national survey, Nagi developed indicators and measurements consistent with the distinctions among pathology, impairment, functional limitations and disability already discussed. His interview schedules included items seeking to determine whether the person interviewed considered his health excellent, good, fair, poor, or very poor. Other items attempted to determine how emotional and physical performance was affected by health impairments.

The study focused on identifying disabilities in two of the most significant spheres of social roles and activities, work and community living. In the work area, persons reported on whether they had no work disability, were limited in work roles and activities, or were vocationally disabled. In the area of community living, they were asked to report whether they had no limitations, were limited but independent, needed assistance to be mobile, or needed assistance in personal care. The data collected, when projected to the total population of the United States between the ages of 18-64, revealed that 4.4% of this group (4,898,473) were limited in their work roles and 6.3% (7,052,112) were vocationally disabled. As related to community living in the total population over 18, 6.3% (8,233,757) were limited but independent; 3.5% (4,464,446) needed mobility assistance; and 1.8% (2,372,781) needed personal care assistance.

It should be pointed out that the data was based solely upon the conditions reported by the persons interviewed. There were no medical or psychological examinations administered. Although a great deal more research is needed, the study clearly indicates, not only the extent of disability in the U.S., but that it is feasible to identify limitations in both work and community living roles.

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#### **Chapter Two**

#### IMPLICATIONS FOR PRACTICE<sup>1</sup>

In the preceding chapter, reference has been made to the importance of developing operational definitions, that is, definitions that can be used by the practitioners of the rehabilitation arts. In this chapter, we shall address ourselves to the application of the concepts of pathology, impairment, functional limitations and disability to the actual practice of these arts. In so doing, we shall relate them, principally, to the field of vocational rehabilitation.

It is evident that, to one degree or another, these concepts and the operational definitions to be developed thereunder will influence the vocational rehabilitation program in a number of areas of concern. These include:

- 1. The social and public policy which underlies the law which authorizes and governs the program
- 2. The determination of eligibility of handicapped individuals and groups for services
- 3. The understanding of an individual's problems and the understanding of the dynamics of those problems
- 4. The planning of services and interventions for individual handicapped persons
- 5. The planning of programs of services for groups of handicapped persons
- 6. The evaluation of the effectiveness and the efficiency of service programs directed at handicapped individuals and groups
- 7. The prediction of outcomes for handicapped individuals of various combinations and sequences of services.

Many of the current problems of vocational rehabilitation (VR) agencies are related to lack of clarity of concepts and lack of operational definitions that can be effectively defended. Among the current problems is whether to revise the definition of mental retardation for VR purposes in light of the new definition of mental retardation adopted by the American Association on Mental Deficiency. If the new definition is accepted, most of the mentally retarded youth in the cooperative VR-public school programs would not be eligible for VR service, or, at least, eligibility would be questioned. Another is found in the acceptance of individuals for service on the basis of "behavioral disorders", a term that recently has been removed from the regulations. This change is expected to reduce substantially the number of public offenders and welfare recipients served by the VR agencies. Particularly acute at this time is the problem of defining the severely disabled, now that the Vocational Rehabilitation Act requires that priority be given to serving such disabled people. Furthermore, the accusation that VR agencies have been "creaming" (accepting the easy cases) is based on confusion or lack of agreement as to who, actually, is disabled, and to what degree.

<sup>&</sup>lt;sup>1</sup>Based upon paper of Barry P. Craig, "Implications of Disability Concepts for Vocational Rehabilitation Practice."

It is evident, then, that the concepts of pathology, impairment, functional limitations and disability, if they are to be meaningful in this program, must be translated into operational terms. Let us, now, look at the VR Act regulations as they relate to eligibility for services and see what changes would be needed to bring into focus the concepts outlined in Chapter One. The basic conditions of eligibility are found in 401.33(b) and as quoted here have certain key terms in parentheses which will be defined immediately following the statement of the basic conditions:

401.33

- (b) Basic conditions. The State plan shall provide that eligibility shall be based only upon:
  - (1) The presence of a (physical or mental disability) which for the individual constitutes or results in a (substantial handicap to employment); and
  - (2) A reasonable expectation that vocational rehabilitation services may benefit the individual in terms of (employability).

Physical or mental disability means a physical or mental condition which materially limits, contributes to limiting or, if not corrected, will probably result in limiting an individual's activities or functioning (401.1(s)).

Substantial handicap to employment means that a physical or mental disability (in the light of attendant medical, psychological, vocational, educational, and other related factors) impedes an individual's occupational performance, by preventing his obtaining, retaining, or preparing for employment consistent with his capacities and abilities (401.1(bb)).

Employability refers to a determination that the provision of vocational rehabilitation services is likely to enable an individual to enter or retain employment consistent with his capacities and abilities in the competitive labor market; the practice of a profession; self-employment; homemaking; farm or family work (including work for which payment is in kind rather than cash); sheltered employment; homebound employment; or other gainful work (401.1(h)).

It should be pointed out that the *physical or mental condition* referred to in the definition of *physical or mental disability* is not defined in the regulation; however, except in an extended *evaluation of rehabilitation potential* as defined in 401.1(i)(5), physical or mental conditions must be "stable or slowly progressive" (401.1(r)) if eligibility is to be based on such a physical or mental condition and *physical and mental restoration services* (401.1(r)) for this condition are to be provided as part of the rehabilitation program.

We shall now attempt to translate these basic conditions of eligibility into the terms of the conceptual definitions found in Chapter One. We shall state the basic conditions in somewhat the same form as the federal conditions, and we shall attempt to define the key terms in parentheses consistent with the previously stated concepts, immediately following the statement of the basic conditions.

- (b) Basic conditions. The State plan shall provide that eligibility shall be based only upon:
- (1) The presence of an (impairment) which results in functional limitations in the individual to such an extent and of such a nature that in the presence of (other individual variables) and (environmental and social factors and demands) the impairment constitutes or results in a (substantial vocational disability or inability); and
- (2) A reasonable expectation that vocational rehabilitation services may benefit the individual in terms of (employability).

Impairment means a physiological, anatomical, or mental loss or other abnormality, or both, whose underlying pathology, if any and if still active (except under an extended evaluation of rehabilitation potential), is stable or slowly progressive.

Other individual variables means other factors in the individual which may constitute or result in limitations such as the reactions of the individual to his impairment and functional limitations, the vocational skills possessed by the individual, the individual's motivation toward work, and the age of the individual.

Environmental and social factors and demands means those factors which exist outside the impaired individual, which associated with his impairment, may constitute or result in a substantial vocational disability. Such factors may include the physical, emotional, mental, and social requirements of work; the vocational skills required by work; and the attitudes of counselors, other professionals, and employers or the community; architectural, legal and transportation barriers or deficiencies; and economic conditions.

Substantial vocational disability means an inability or limitation in performing the roles and tasks of the vocational or work sphere of life due to the presence of and/or interactions among impairment, other individual variables, and environmental and social factors and demands, which inabilities or limitations impede the individual's occupational performance, by preventing his obtaining, retaining, or preparing for employment consistent with his capacities and abilities.

Employability refers to a determination that the provision of vocational rehabilitation services is likely to increase or augment the individual's ability to perform the roles and tasks of the vocational sphere of life, by reducing his impairment, mitigating the adverse effect of other individual variables, and/or modifying the environmental and social factors and demands to the extent that the individual can enter or retain employment consistent with his capacities and abilities in the competitive labor market; the practice of a profession; self-employment; homemaking; farm or family work (including work for which payment is in kind rather than cash); sheltered employment; homebound employment; or other gainful work.

It has been pointed out that the federal term handicap and the term disability used in this paper may not be equivalent. In making the above translation it has been assumed that they are approximately synonymous. It has also been assumed that the federal term disability is a term

containing more or less the meanings of our terms pathology, impairment, and functional limitations. If these assumptions are valid and if the reformulation of the basic conditions given above is an accurate translation of our concepts, several observations can be made. In many respects the two statements of basic conditions are similar; however, by using these concepts we can clarify and distinguish certain aspects which are not very well delineated conceptually in the federal conditions. In the reformulation we can better distinguish the following variables:

- 1. Pathology (active and inactive)
- 2. Impairment
- 3. Functional limitations directly resulting from the impairment or indirectly resulting from the impairment.
- 4. Other factors in the individual which may be limiting, but which are not a direct result of the impairment.
- 5. Relevant environmental and social factors and demands which exist outside of the individual
- 6. Vocational and other inabilities resulting from the interaction of these variables.

The delineation of these variables implies that vocational ability might be enhanced by interventions at several points. We might augment employability by:

- 1. Treatment of *pathology* (if present)
- 2. Reducing the *impairment* (and/or *functional limitations*) through prostheses, physical therapy, occupational therapy, or education and social adjustment training (e.g., in mental retardation and chronic mental illness)
- 3. Mitigating the effects of *other individual variables* through psychotherapy and counseling, vocational training, work adjustment training, education, career re-direction (e.g., in elderly persons)
- 4. Changing or modifying the *environmental and social factors and demands*; i.e., by shifting the focus of change from the client to the environment in which the client will function, by such measures as:
  - (a) Changing living arrangements: from family or institution to a group home, from rural to urban or urban to rural, less structured to more structured and supportive, from a place where the client and his problems are widely known to a place where the client may get a new start, etc.
  - (b) Providing family therapy
  - (c) Job re-engineering
  - (d) Attitude change interventions with the employer and fellow employees and the community (e.g., to modify attitudes toward people bearing certain labels)

- (e) Client advocacy (legal and political)
- (f) Providing recreation after work hours
- (g) Removing or reducing architectural barriers
- (h) Providing psycho-social support systems (e.g., small group homes, friendly visitors)
- (i) Providing follow-along services to insure maintenance of the changes in environmental and social factors and demands which prevent vocational inabilities.

In vocational rehabilitation practice the ability to distinguish among the variables mentioned previously is a very important one for client study, eligibility determination, program planning, and program evaluation. The full value of such delineation, however, can only be realized if we have empirically valid and reliable methods for measuring these variables and empirically valid theoretical models for relating these variables to one another. Our most highly developed methods of measurement at the present time are in the area of pathology; however, there are many deficiencies in our knowledge, systems of classification, and conceptualization of emotional and intellectual pathology. When we consider impairment, we have fairly good measures for physical impairments, but our ability to describe emotional and intellectual impairments is subject to many of the same deficiencies mentioned in connection with emotional and intellectual pathology. As we examine the other variables we have good methods of measurement for some aspects of these variables, but other aspects are very difficult to measure. The outstanding difficulty we see at this time is our limited ability to relate one variable to another in such a way as will enable us to understand the client's problems and their dynamics to plan services and interventions, to predict outcomes of services, to evaluate programs, to plan programs, and to perform such other essential tasks in vocational rehabilitation practice.

In conclusion, it may be said that, although the conceptual definitions of pathology, impairment, functional limitations, and disability are accepted, and their value for program planning and, possibly, program evaluation, is recognized, operational definitions must be much more precise before the concepts can be used effectively by the rehabilitation counselor and other professionals with direct service responsibilities.

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#### Chapter Three

#### IMPLICATIONS FOR RESEARCH<sup>1</sup>

In this chapter we shall consider the implications the concepts of pathology, impairment, functional limitations and disability set forth in this paper have for research and researchers.

Before we do this, however, four attributes of this concept of disability serve to stand out and are important to what we expect to say.

#### (1) Disability Is Relational

The definition is rooted in the person-in-the-environment. In view of the relational or interactive character of disability, it is therefore conceivable that disability can be reduced and possibly eliminated as a result of environmental alteration. For example, one with the disability of blindness might experience substantial reduction in disability as a result of technological changes that allow a blind person to "read" printed material through the use of devices that allow for the transfer of visual material into a tactile sensory mode. The relational or interactive character of a disability allows for considerable fluidity since it is not exclusively a function of the intrinsic attributes of the individual.

#### (2) Disability Is Inference

In this definition, disability is an inference. The point to emphasize here is that disability in this definition can never be directly observed. Physical or mental dysfunction can be the subject of direct observation. Disability cannot. This brings us to our next point.

#### (3) Disability Is a Discrepancy

That disability is not the subject of direct observation is a necessary consequence of its definition as a discrepancy between individual performance and average expectable role performance. Coming at the same issue from a different angle, it is possible to describe disability as norm-referenced. In other words, the inference that "John is disabled" presupposes not simply a measure of John's performance, but also a measure of how people like John normatively perform in a specific role.

#### (4) Disability Is a Consequence

In the definition, a disability is consequent to the existence of a physical or mental impairment. Such a statement might seem as a round-about way of saying something quite simple. Namely, that disability is *caused* by physical or mental impairments. Without getting into a discussion of the philosophical issues involved in the attribution of causality, suffice it to say that purposes of simplicity are better served if the view is preserved of disability as consequent to rather than caused by physical or mental impairments.

<sup>&</sup>lt;sup>1</sup>Based on paper of Joseph B. Moriarty, "Disability Concepts: Implications for Research."

#### Rehabilitation Potential Reconsidered

In the next four paragraphs, we expect to relate the stated concept, disability, to the determination of rehabilitation potential of an applicant for rehabilitation services. Other parts of the rehabilitation process could be used, but it seems that the determination of rehabilitation potential, being at the heart, the rehabilitation process offers most promise for illustrative purposes.

Before proceeding with this discussion, it might be helpful if we derive some sense of what is meant by the term rehabilitation potential. Rehabilitation potential refers to the probability that disability will be reduced or eliminated given the provision of rehabilitative services. As used in rehabilitation circles, the term rehabilitation potential usually refers to the probability of an individual securing or engaging in productive employment. In terms of our definition, therefore, rehabilitation potential relates to the reduction of work disability. From the standpoint of vocational rehabilitation, reduction in disability of independent living is usually viewed as an instrumental goal with the reduction of work disability being the ultimate goal.

As I review rehabilitation literature, I am struck with the overriding sense with which rehabilitation potential is used to denote an entity that largely inheres in the disabled person. "John has rehabilitation potential." This attribution of rehabilitation potential as a characteristic inherent in John is common in rehabilitation practice and research. Consistent with this assumption, one comes across much research in the area of rehabilitation potential that almost exclusively concerns itself with properties of the client or disabled individual. The client's work history, the client's psychological test scores, the client's interest and attitude—variables such as these predominate in attempts at pinpointing the client with "good" rehabilitation potential.

The point here is that rehabilitation potential is defined as the likelihood that disability will be reduced. But if disability in turn is defined in social or environmental terms, so too the concept of rehabilitation potential needs to be broadened to include this conceptualization.

Thus, our conceptualization of disability requires a revision in the concept of rehabilitation potential, in the direction of an interactive model wherein individual client factors and environmental factors interact to produce rehabilitation potential as a product. We must consider at least three environments: that of the family and the significant others in the disabled person's life, the rehabilitative environment, and the broader labor-economic and social environment in which both client and rehabilitative enterprise find themselves. The rehabilitative environment is defined as the sum total of restorative goods and services functionally available to the disabled person.

This interactive definition of rehabilitation potential doesn't make an assumption of environmental homogeneity. Rather, it asserts that (for example) family environments both vary and have an impact on rehabilitation potential. Those familiar with rehabilitation are aware that variations in the family functioning of the individual disabled can have a profound effect on the probability of disability reduction. Put another way, things like psychological and economic family health have predictable impact on rehabilitation potential.

Similarly, this interactive model allows for heterogeneity in rehabilitation environments. Those with even a nodding familiarity with rehabilitation know there is wide variation both from state to state and within a particular state as to the rehabilitation facilities. Other areas are virtually lacking in these facilities. What's more, there is considerable variation *between* facilities as to quality and extent of services.

Turning to the third environment mentioned above, prevailing local unemployment rates is but one of the more obvious examples of how forces in the labor-economic environment interact with characteristics of the individual to influence probability of employment and therefore rehabilitation potential.

#### Implications for Research

What, then, are the implications of this concept for research? The discussion in this section is divided into two parts. The first part will deal with implications for research at a global or overall level. In the second part, specific strategies and approaches will be suggested. First let us look at the more general implications.

(1) Development of linkages between rehabilitation research and practice must be emphasized. We refer to two kinds of linkages: conceptual and methodological. The implementation of research strategies consistent with the definition of rehabilitation potential herein set forth will require a significant escalation in the complexity of research over that which has gone on in the past. Such an escalation is, however, required since the subject matter under investigation is not a simplistic one.

The probability of such research strategy being implemented will be influenced to a significant degree by the development of greater conceptual linkages between rehabilitation research and practice. Practitioners, lacking formalized training in research methodology, are understandably reluctant to integrate research as part of their functions. Yet, the professionalization of the research role can lead to a confusion of goals with methods. Complicated statistical manipulations and sophisticated experimental designs represent a method for the pursuit of inquiry. The goal is generation of knowledge. Methodology is a tool for the attainment of this goal. The practitioner is not to be faulted if he sees precious little similarity between this formalization and his role.

However, the position set forth here is that a closer scrutiny of the researcher role and the practitioner role particularly in rehabilitation will reveal greater points of conceptual similarity than that revealed by superficial observation. The research process reveals a procedure marked by observation, the development of hypotheses based on observation and the testing of these hypotheses. Hypotheses are then confirmed, modified or rejected based on the outcome of the testing process.

As one transfers over and looks at the rehabilitation process, one sees a process that is conceptually quite similar. The rehabilitation process involves first of all an observational or data collection phase. These two steps are quite similar to the research process of observation and hypothesis formulation. Good rehabilitation practice (like good research practice) underscores the need to question constantly the accepted assumptions about the nature of disability. Conceptually, the disparity between this self-monitoring aspect of the rehabilitation process and the hypothesis testing phase of research functioning is minimal.

In sum, therefore, the congruence between the rehabilitation model and the research model is quite high, such that the practitioner-as-experimentalist is a term whose application does minimum violence to reality. The implementation of a research strategy consistent with already defined concept of rehabilitation potential would be significantly hastened if this aspect of the practitioner role were identified, encouraged and refined.

Refinements might include the development of observational schemes that would capitalize on the practitioner's skill as a trained observer. The pooling and codification of observation made in turn could form not only a rich base for hypothesis generation, but also constitute an intrinsically valid method for hypothesis testing.

On this latter point there is ample historical support. In the behavioral sciences, one immediately thinks of the methods of a Freud or a Piaget. One combs through the work of these investigators and looks in vain for the presence of a single statistic. Yet, few would refute the knowledge contribution of either.

(2) Environmental factors must be included in research. The view of disability as a disturbance in role functioning and the consequent conceptualization of rehabilitation potential in individual environment terms will require a greater emphasis on environmental measures in rehabilitation research.

Historically, the model of service delivery in rehabilitation has drawn heavily from the medical and counseling psychology models. Both of these models emphasize an intervention strategy that is rooted in the dyadic relationship, whether it be doctor-patient or counselor-client. The strength of these historical antecedents is such that rehabilitation research and practice often seem to be characterized by a preoccupation with the dyadic as a prime intervention strategy.

The acceptance of the definition of rehabilitation potential as an interactive concept calls for the development and/or utilization of measures that transcend the dyadic.

Data reported in Dr. Nagi's prevalence research highlights this need. He reports that approximately only one-third of the variance in work disability could be explained by eight factors intrinsic to the individual; i.e., physical performance, health status, number of conditions, education, emotional performance, sex, age, and race. What's more, because of the methodological limitations of survey research, it is possible that the findings of one-third variance being explained by intrinsic conditions might be spuriously high. This arises from the fact that the source of information on work disability and the source of information on four of the eight intrinsic factors mentioned above resulted from the answers of the respondents. As a specific example, the measure of work disability was the verbal report of the respondent. Similarly, the measure of physical performance was derived from the verbal report of the same individual. This method dependence is likely to add to whatever underlying relationships in fact exist between physical performance and work disability. If these two measures were method independent (for example, if the measure of physical performance were the result of behavior on a standard set of tasks such as lifting, walking, etc.) the resultant relationship of an index of physical performance so derived would then be method independent of the verbal report of a respondent as to work disability. We would then not be surprised if the use of method independent measures were accompanied by a reduction in the amount of common variance shared by physical performance and work disability. Similar reductions in the amount of common variance on other method dependent indices (health status, number of conditions and emotional performance) could also be expected to reduce the amount of variance in work disability associated with factors intrinsic to the individual.

So the underlying association of factors intrinsic to the individual on the one hand, and work disability on the other may not even be as high as the one-third finding of Dr. Nagi. But even if the

one-third figure is accepted, it still leaves two-thirds of the variance unaccounted for. Such a finding lends cogency to the inclusion of relevant environmental measures in research on rehabilitation potential.

As a concrete example, attention is directed to the fact that recent rehabilitation legislation has incorporated an affirmative action provision for employers on behalf of the handicapped. Variance associated with the extent to which this provision of the law is implemented provides an occasion wherein the influence of environmental factors on rehabilitation potential can be assessed.

As one examines the impact of environmental forces, one is naturally inclined to think of disciplines such as sociology, economics and related social sciences. It seems appropriate, therefore, to call on increased involvement from such disciplines as one expands the concept of rehabilitation potential. Instrumentation developed in these sciences should be reviewed, adapted or refined as rehabilitation research moves out of a preoccupation with the dyadic.

(3) Interaction effects must be analyzed. Rehabilitation research of the future needs to place greater stress on analyzing interactions and not simply main effects. Multi-factorial research designs incorporating logically related indices would increase the goodness of fit between research and the world of the practitioner, administrator and policy maker.

The difference between main effects and interaction effects can be illustrated by research done on rehabilitation intervention. Main effects analysis in the area of counseling would focus on the impact of counseling on selected dependent measures. Interaction analysis would deal with the differential impact of counseling as it interacts with (for example) educational level of the counselee, prior work history, family functioning, etc.

(4) Specification of locus of effect. As one moves toward an acceptance of a multivariate definition of rehabilitation potential, the need is clarified for including greater specificity. Hypotheses about locus of effect must be more specific. To illustrate, return to the previous example regarding the effects of counseling. Counseling is a coarse-grain term denoting a virtually limitless set of activities. A fine-grain analysis of this intervention strategy would focus on what specific activities on the part of what kinds of counselors lead to what kinds of effects.

#### Specific Recommendations

1. Development of instrumentation. The work of many scholars focuses our attention on the need for more adequate instrumentation. Problems associated with an exclusive reliance on verbal report were referred to above. Borrowing concepts from the behavioral sciences and examining those aspects of rehabilitation that relate to properties of the individual, one can discriminate between method and trait. The latter is defined as some characteristic of an individual that is relevant to a particular discussion. In the context of rehabilitation, traits such as work disability, disability in independent living, emotional performance, physical performance, can be regarded as rehabilitation-related traits conceptualized as characteristics of the individual.

The notion of method is concerned with a particular instrumentation selected because of a presumed or demonstrated relationship to a particular trait. In Dr. Nagi's research, for example (referred to in Chapter One), the verbal report of the respondents on a seven-item scale (dealing with degree of difficulty in such activities as walking, stooping, etc.) was the method used to

measure the trait of physical performance. It is recommended that multiple methods be developed for the measurement of those traits that are crucial to rehabilitation. As an example, one method for measuring the trait of physical performance is the self-report of the respondent. A second method for measuring the same trait is the report of significant others. A third method, as indicated above, is the observed performance of an individual on a standard set of exercises.

Similarly, multi-method measures could be developed for other crucial traits such as work disability. In addition, the concept of disability as a disturbance in role functioning presupposes, as was earlier suggested, a normative view of disability. In terms of instrumentation, this entails the necessity for norm-referenced standards as to what constitutes expectable role performance. Such instrumentation would prove of considerable value both for operationally defining disability, as well as providing a base line against which to evaluate recovery of function, whether such recovery occurred spontaneously or as a result of programs of remediation.

- 2. A combination of longitudinal with cross-sectional research is needed. Practical considerations often dictate research strategy. Funding for research is usually on a time-limited basis. Correspondingly, the behavior of researchers is shaped in the direction of preparing and submitting proposals that emphasize a cross-sectional approach to the study of phenomenon. Cross-sectional research typically involves the development of multiple measures on a relatively large number of individuals at or close to the same point in time. Longitudinal strategies, in contrast, involve the sequential observation and measurement on individuals across time. It is suggested that the implementation of a research strategy geared toward an interactive concept of disability requires the careful observation of individuals over time as a necessary complement to cross-sectional approaches. Viewing rehabilitation potential as the dynamic interplay of individual and environmental factors places increased needs for the utilization of research strategies that are consistent with such a view. It is not within the purview of my assigned task to elaborate in detail on the relative contribution of cross-sectional vs. longitudinal approaches. It will suffice to say that a central concept in rehabilitation is the restoration assumption. Restoration implies a return to a chronologically earlier level of role performance. Longitudinal strategies are uniquely equipped to examine and explore such time-sequential phenomena.
- 3. Centralized planning of large-scale research efforts is a must. The logistics of conducting research consistent with the model that I have tried to put forth in this paper is a significant one. Large-scale interdisciplinary efforts create significant need for centralized planning, instrumentation, development and utilization, etc. Within rehabilitation we lack precedent for this type of an effort. Organizations such as the National Rehabilitation Association, in cooperation with other private and governmental agencies as well as professional and scientific organizations, are in a position to significantly facilitate the management of a research enterprise similar to what appears to be needed.

#### Chapter Four

## DISABILITY CONCEPTS: IMPLICATIONS FOR PROGRAM AND POLICY DEVELOPMENT<sup>1</sup>

The distinctions between impairments, functional limitations and disability have important consequences for the development of programs and policies dealing with the prevention, amelioration and consequences of disability. The confusion or identification of impairments with disability, for example, has several sources. From the standpoint of administrative convenience, impairment criteria have the advantage of the relative simplicity of attributes. Attribute measurements offer simplicity, standardization and reliability for routine decision making. Relational concepts, such as disability, are more complex. They require not only the measurement of several aspects of the relationship, but also the nature of the interrelationship of these attributes. If complexity is required for validity, and simplicity is conducive to reliability, then the organization dilemma may be characterized in terms of the trade-offs between accountability, in the form of measurable reliability, and validity, as potentially unknowable or metaphysical "truth.' From such organizational dilemmas spring the proliferation of regulations to define, circumscribe, elucidate, and operationalize the legislative intent embodied in the statutory language or definitions. Such concerns are also frequently the source of the arcane and painstaking search through congressional hearings and reports to determine what was really the legislative intent.

Another aspect of the confusion between impairment and disability lies with two different traditions of terminology and usage, springing from the psychological and rehabilitation focus on impairments within the context of treatment, and the tradition of disability evaluation, rooted in the wage replacement and income maintenance programs of Workmen's Compensation and Social Security disability insurance (DI). In neither case, of course, does the focus on impairments or work requirements completely dominate. The goal of vocational rehabilitation is employability; the primary determination in disability evaluation is usually the severity of impairment. In some states workers' compensation determinations, for example, are purely impairment decisions, with disability evaluations, in the relational sense, entering only into questions of permanent impairment and adversary actions. In other states, an effort is made to evaluate wage loss. Despite these similarities, however, the two traditions of disabilities and rehabilitation evaluation represent somewhat different orientations and emphases towards the assessment of incapacity.

The emphasis on the impairment attributes rather than on disability relationships has also had direct effects on the beneficiary or target populations in terms of the diversion of effort and interest from environmental adaptations for the disabled to restorative potential and adjustment of the disabled, frequently in areas and conditions in which little capacity for restoration exists or to the disservice of entire segments of the disabled population. This can be seen, for example, in the congressional reservations about broadening the disability concept to encompass employability. "Unemployability" has generally been considered a matter of employment practices rather than of disability, and has been specifically excluded from consideration in disability determination under Social Security. However, the age, education and vocational factors in the Social Security disability regulations and the special provisions for older workers both represent aspects of employability.

<sup>&</sup>lt;sup>1</sup>Based on paper by Lawrence D. Haber, "Disability Definitions: Implications for Program and Policy Development."

Special provisions for the blind which modify the employment capacity requirements are also a form of employability measure, for a specific impairment classification and an occupational disability variant. The recommendations of the Subcommittee on Disability of the American Public Welfare Association, to revise the recently enacted provisions for the disabled under the supplemental security income (SSI), focus directly on the issue of unemployability, in the special case of disabled welfare recipients. In each of these cases, of course, the question is the extent to which the impairment contributes to the inability to meet work requirements or "to engage in substantial gainful activity." Concepts of unemployability and occupational disability simply take greater account of what the disabled person is able or allowed to do rather than what he "should be able to do" on the basis of his physiological impairments or functional limitations.

#### Definitions of Disability—Alternative and Complementary

To clarify the relationship between disability criteria and the effects on programs, it would be useful to examine some specific program definitions. Although it is generally accepted that program definitions reflect program purposes, there are questions as to the extent to which program purposes reflect the legislative programmatic impulse and the extent to which they reflect the emergent administrative objectives and originational requirements of the defining organizations. The requirements of objectivity, for example, may override those of adequacy or accuracy. Resource limitations and statutory restrictions may also interpose marginal objectives, in the attainment of programmatic goals. As in any well-run organization, the attainment of the "do-able" is usually preferred to failure at the optimal

Five definitions of disabled and handicapped persons currently in use among programs within DHEW have been selected. These include vocational rehabilitation, the new anti-discrimination statutes, special education requirements for handicapped children, vocational education requirements, and the disability benefits provisions for disability insurance (DI) and supplementary security income (SSI). These definitions cover a wide array of alternative criteria and a broad range of programs.

#### **Definitions of Handicapped Person**

- 1. Vocational Rehabilitation
  - a. Statutory definition for Titles I, II, III (Rehabilitation Act of 1973, as amended (1974))

The term "handicapped individual" means any individual who (A) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment and (B) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services provided pursuant to Titles I and III of this Act. 29 U.S.C. 706(1).

#### b. Regulations

"Handicapped individual" means an individual (1) Who has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment; and (2) Who is expected to benefit in terms of employability from the provision of vocational rehabilitation services, or for whom an extended evaluation of rehabilitation potential is necessary for the purpose of determining whether he might benefit in terms of employability from the provision of vocational rehabilitation services.

"Physical or mental disability" means a physical or mental condition which materially limits, contributes to limiting or, if not corrected, will probably result in limiting an individual's activities or functioning.

"Substantial handicap to employment" means that a physical or mental disability (in light of attendant medical, psychological, vocational, educational, and other related factors) impedes an individual's occupational performance by preventing his obtaining, retaining, or preparing for employment consistent with his capacities and abilities. 45 CFR 401.1.

#### 2. Discrimination

a. Statutory definition (Section 504 of the Rehabilitation Act of 1973, as amended, 1974)

A handicapped individual is any person who (A) has a physical or mental impairment which substantially limits one or more of such person's major *life* activities, (B) has a record of such an impairment, or (C) is regarded as having such an impairment.

#### 3. Disability Benefits (DI and SSI)

a. Statutory definitions (Social Security Act, as amended)

The term "disability" means (A) inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to last for a continuous period of not less than 12 months; or (B) in the case of an individual who has attained the age of 55 and is blind (within the meaning of "blindness" as defined in section 416(i)(1) of this title), inability by reason of such blindness to engage in substantial gainful activity requiring skills or abilities comparable to those of any gainful activity in which he has previously engaged with some regularity and over a substantial period of time. 42 U.S.C. 423(d)(1)

For purposes of this subsection, a "physical or mental impairment" is an impairment that results from anatomical, physiological, or psychological abnormalities which are demonstrable by medically acceptable clinical and laboratory diagnostic techniques. 42 U.S.C. 423(d)(3).

#### b. SSA regulations

A physical or mental impairment is an impairment that results from anatomical, physiological, or psychological abnormalities which are demonstrable by medically acceptable clinical and laboratory diagnostic techniques. Statements of the applicant, including his own description of his impairment (symptoms) are, alone, insufficient to establish the presence of a physical or mental impairment. 20 CFR 404.1501(c).

#### 4. Vocational Education

a. Statutory definition (Vocational Education Act of 1946, as amended)

The term "handicapped," when applied to persons, means persons who are mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, crippled or other health impaired persons who by reason thereof require special education and related services. 20 U.S.C. 1248(b).

#### b. OE regulations

"Handicapped persons" means mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, crippled, or other health impaired persons who by reason of their handicapping condition cannot succeed in a vocational or consumer and homemaking education program designed for persons without such handicaps, and who for that reason require special educational assistance or a modified vocational or consumer and homemaking education program. 45 CFR 102.3(o).

#### 5. Special Education

#### a. Statutory definition (Education of the Handicapped Act of 1970)

The term "handicapped children" means mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, crippled, or other health impaired children who by reason thereof require special education and related services. 20 U.S.C. 1401(1).

#### b. OE regulations

"Handicapped children" means mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, crippled or other health impaired children who by reason thereof require special education and related services. The term includes children with specific learning disabilities to the extent that such children are health impaired children who by reason thereof require special education and related services. 45 CFR 121.2(j).

A quick review of the definitions shows the diversity of requirements and criteria used. The vocational rehabilitation (VR) definitions, for example, require that the physical or mental "disability" result in (a) a substantial handicap to employment and (b) a reasonable expectation that VR services will enhance employability. The discrimination definitions (Sec. 504) require only physical or mental impairment substantially limiting "major life activities." In addition to the broad area of participation or performance covered under major life activities, the statute includes not only those now restricted by an impairment, but those who may be restricted by having had or having been regarded as having such an impairment. Since the language of the legislation goes beyond work and VR services to include a broad array of social services, the population covered against potential discrimination may include infants, students, and the elderly, as well as those whose handicaps preclude them from employment.

Social Security statutes focus on "inability." The regulations define "substantial gainful activity," and specify what is meant by a "medically determinable physical or mental impairment." Duration of disability is defined—expected to result in death or to last twelve months or longer. A specific modification is included for blindness, narrowing the requirements for substantial gainful activity to work "requiring skills or abilities comparable to previous accustomed activity. An extensive body of regulations defines each element of this definition as well as of the related requirements of the "waiting period" and "disability insured status."

The fourth and fifth definitions deal with education and specify a number of specific disorders and impairment which may lead to the requirement for special education and relative services for children and adults.

Comparing these definitions, we may note several common elements and a few unique elements. The first three definitions, for example, refer to the generic category of "physical or mental impairment," in contrast to the education service definitions, in which the handicapped are defined by reference to specific conditions or impairments, such as mentally retarded, visually handicapped and emotionally disturbed. Two definitions, the VR and SSA definitions, refer specifically to employment in the general sense of "handicap to employment" or as "inability to engage in substantial gainful activity."

Section 504, the anti-discrimination definition, uses a much broader measure of performance limitations, as "major life activities." The two education definitions do not specify the nature of the limitations other than the requirement for "special education." These two definitions and the VR definition stipulate the service benefit as "requires" or "can benefit" from the proffered services. Only one definition, SSDI statutes, states any requirement or limitation on the nature of the impairment or condition as "medically determinable."

It is clear that certain elements of these definitions are directed to and are a reflection of program objectives and the services to be provided. The VR definition, for example, emphasizes both need—the handicap to employment stemming from the impairment—and ability to benefit from such services. The provision of services to the "unmotivated" or to those whose employability cannot be improved by services is not intended. The SSA definitions for DI and SSI purposes, on the other hand, revolve around proof of incapacity, as a condition for eligibility for income maintenance benefits intended to replace wages lost through the incapacity to engage in substantial employment. The criteria therefore, are designed to exclude those whose entitlement would be considered as dysfunctional or contrary to the public interest because of their residual capacity for work. The anti-discrimination provisions extend to all areas of social participation classified under "major life activity," regardless of the contribution to economic loss or limitation occasioned by the impairment.

The most redundant statements are in the educational requirements, which specify conditions and impairments which are neither inclusive nor exhaustive and which, in any case, are covered by the general provision for "health impaired persons." The education statutes also provide the least information or guidance as to the process, nature or extent of limitation which precludes general education. The definition in OE regulations of "health impaired persons who by reason of their handicapping condition cannot succeed in a vocational or consumer or homemaking education program designed for persons without such handicaps," and who therefore require a modified or special education program is a restatement rather than an expansion of the statute. This would suggest that the decision process for the choice of eligible persons and of services is primarily or entirely the jurisdiction of the local or State school system. In contrast, the DI-SSI regulations and the anti-discrimination provisions appear to leave little discretion in the hands of the individual examiner.

The primary responsibility for eligibility determination in the VR program obviously rests with the counselor or agency who makes the determination whether the handicapped or disabled individual "can benefit in terms of employment from VR services." These procedures would imply that the VR gatekeepers retain primary control over access to and selection of services.

In the anti-discrimination and DI-SSI provisions, the adjudicators are relatively circumscribed by the statutes and regulations. Claimants and clients are basically self-selected with, at least in theory, little subjective input from the adjudicator. Despite the basic VR commitment to self-selection of applicants, most income-maintenance programs require, at least formally, that claimants also accept referral to VR, as in Workmen's Compensation, SSI and DI and public assistance programs.

Among these programs, the SSA provisions have two unique features not shared by any other programs: one, a durational requirement of twelve months or longer, and two, a waiting period of approximately six months before income maintenance benefits can be received. These provisions are intended to insure that only those persons whose behavior is subject to extensive and continuing modification because of their disability will become entitled and that a sufficient period of time elapses to provide a sound administrative basis for evaluation and adjudication.

Given the difference in program purposes, objectives and services of the programs examined here, is there any value to considering a general definition of disability which will subsume in some way the attributes considered and the services offered under the various programs? While there would appear to be little question of the value of comparable and generalizable definitions for research purposes, it is extremely doubtful that the programs considered would benefit from a common definitional base.

There is, however, a good deal to be said for the use of complementary and interrelated definitions within certain areas of program responsibility. Although DI, Workers' Compensation and the Veterans' Programs have a number of unique features which differentiate one from another, they all share a common concern with the effect of impairments on capacity for employment and work. The development of a common core of concepts, operational definitions and measurements in these areas could be extremely useful for adjudicating entitlement and incapacity in an equitable manner among these programs. The relationship of these standards to the standards in use in private insurance programs also deserves some consideration. At the very least, claimants should be able to understand the reasons why they can be eligible under one program and denied under another, when both purport to provide a similar benefit for the same or similar performance incapacity, based on the same impairments or limitations.

When the welfare reform legislation federalizing the State grant-in-aid disability programs (APTD-AB) was being considered, the disability determination procedures for DI, APTD and the incapacitated parent segment of the Aid to Families with Dependent Children (AFDC) procedures was reviewed, along with the referral process of the VR agencies (National Task Force on Welfare Reform and Rehabilitation Planning, 1972). At the time, it was recommended that the same disability process be followed for SSI as was used in DI, with the same or similar definitions. A related definition was recommended for "incapacity" as "a medically determinable physical or mental impairment which by itself or in conjunction with age, education, vocational experience, and similar barriers to employment, prevents an individual from engaging in suitable work."

The recommendation for the "incapacity determination" is similar to the recent recommendations of the APWA, to take account of the concerns now being expressed about purported or potential inequities produced by the change from the APTD standards. While the concern with this problem is very real in the welfare community, the factual basis for assuming that

any substantial number of people have been denied under the SSI procedures who might otherwise have been found eligible under the State-administered APTD-AB provisions is very scanty. The feeling exists, however, that when DI and APTD were separately administered, APTD represented a kind of fall-through, under which needy persons found ineligible for the federal program might still be found eligible under the State-administered program. With the combination of both programs under the same federal administration and with the same definition of disability, this, of course, is no longer true. Those found eligible for one on the grounds of disability are ineligible for both. Of course, aside from any questions of inequities created by consolidated administration, the real question remains whether people eligible by virtue of need under the welfare programs are so different in their characteristics, composition and social and work history as to require a different set of criteria or adjudicative practices.

Since all of the disability programs being considered also had a VR referral requirement, the Task Force also proposed that similar or compatible referral screening guides should be developed, to insure that claimants who could benefit from VR services would have access to them and that those for whom rehabilitation was not feasible would not be referred to the VR agencies, who would otherwise be flooded with inappropriate applicants.

The criteria of "handicap to employment" in the VR definitions is obviously directly applicable to claimants in this group, whether DI, SSI or incapacitated parents under AFDC. The question of ability to benefit from services, of course, is considerably more difficult and ambiguous, particularly among that relatively large proportion of the welfare groups with unstable, erratic or marginal work histories, limited job skills and little education. The screening criteria proposed by the Task Force would almost automatically screen out the vast majority of these claimants on the basis of work history, nature of the work performed, aptitude, academic attainment, age, and in many cases, attitude or motivation for work. The screening criteria in use for DI referrals to VR are such as to automatically screen out the vast majority of DI claimants. Relatively few DI beneficiaries survive the various screening levels to actually arrive at the receipt of services. Less than a fifth are referred for services, and only two-thirds of those are closed rehabilitated.

Among all VR closures, the record is somewhat better, but not overly encouraging. Of the roughly one million closures in 1974, about half were closed out without receiving services; only a third were rehabilitated, including those rehabilitated for housework. The rehabilitation benefits for some of these cases were, in all probability, relatively marginal and transitory; significant proportions had no earnings in the year following rehabilitation.

The relatively low order of effectiveness of VR services for the long-term disabled in need of income maintenance services again suggests the importance of developing an extensive and rational early case management system through a sickness and injury benefit program. There would also appear to be some necessity for obtaining a better understanding of the circumstances in which VR services will be of benefit to the long-term and severely disabled. This does not, however, require the creation of common or inclusive definitions for the populations to be covered by VR and income maintenance programs.

On the other hand, there does seem to be a great deal of similarity between the services offered under the VR program and those available through special and vocational education programs. The examination and elaboration of compatible definitions and program relationships could provide a better delineation of the problems and alternatives in the allocation of services.

The data in Nagi's study (1975: 24-36) also provide some interesting insights into the problems of defining work disability, as compared to physical performance limitations. Prediction of work disability is relatively poor and is considerably poorer than for physical performance. A small number of variables accounts for 62 percent of the variance in physical performance of the study population. However, even with more independent variables, including the physical performance measure, only 38 percent of the variance in work disability could be accounted for by sociodemographic, health and physical performance measures.

These findings reinforce our understanding of the problems of relational concepts as against attribute concepts. Unlike physical performance, work disability requires not only an assessment of the sociodemographic and health characteristics of the individual, but also of the attributes of accustomed or available work, the community and economic environment, the state of the economy and the relationship of labor supply and demand. Hopefully a study now being undertaken cooperatively by SSA and the University of Massachusetts will throw more light on the factors affecting the prevalence of disability as manifested by community disability rates.

This relatively brief review of a few selected disability program definitions was intended to point out some of the problems of administration, of coverage, of adequacy, and of inequity produced by the legislative and regulatory definitions of disability. The origins of many of these problems are, of course, not a question of a lack of understanding or indifference to the problems of the disabled and handicapped. Political and administrative considerations are often of equal or overriding concern; the statutes and regulations which emerge from these considerations are frequently a compromise between the obtainable and the desirable.

Discussions of program and policy development tend, of necessity and by intent, to focus on their problems and inadequacies. The tremendous importance of these programs in providing income, rehabilitation, education and equal opportunity services to a large number of handicapped and disabled persons should not go unremarked, despite the limitations of any or all of these programs. They pay basic support benefits to more than 3 million people a year, provide rehabilitation services to more than a half a million people and offer special education to 3 million handicapped children a year. The fact that most of the studies evaluating the attainments and shortcomings of these governmental programs are themselves governmentally supported is itself an indication of the interest and commitment to program improvement. Neither the virtue of the program nor the commitment of its sponsors or administrators is, however, a sufficient guarantee or condition for objective efficiency. They are, however, a necessary condition for critical review and planning to enhance program contributions to the general welfare of the handicapped and disabled members of our society.

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## **Chapter Five**

#### IMPLICATIONS FOR SERVICE DELIVERY

In this chapter, we shall discuss the implications of our findings for structuring the delivery of human services. This is a major concern of state legislatures and the Federal Congress, as well as program managers, many of whom seem to feel that the present structures of social programs have developed more by the variety and chronology of governing statutes than by sound general planning, and that they have little relevance to the problem faced by disabled and otherwise disadvantaged people.

Already, in this report, reference has been made to the difficulties in getting a meeting of minds of administrators and researchers, and some suggestions have been made for improving this situation. The problem is emphasized here, because its solution will be required in the area of service delivery systems as well as case service practices, if order is to come out of what many consider a chaotic situation.

As they attack the problem of developing a viable delivery structure, it is essential that, to the degree possible, administrators, practitioners, and researchers agree upon the principles they feel are important to guide their efforts; agree upon the validity of the data base; understand their respective biases; and understand their own and other programs.

In the meantime, of course, as this research is being done, the work must go on, and administrators will have to structure their delivery systems the best they can on the basis of available facts and intuition.

### Restructuring Services

Let us now relate the structuring of services to the four entities to which we have addressed ourselves throughout our deliberations: pathology, impairment, functional limitations, and disability. Pathology (illness and pathophysiologic response) is dealt with in the health care system, although it may be a factor throughout the rehabilitation process. Impairment is dealt with through restorative health care and prosthesis or through indemnification for anatomical loss of function (Workmen's Compensation and VA). Functional limitations respond to environmental modifications and retraining of various kinds and at various levels. Disability is dealt with through rehabilitation, employment, education and income maintenance.

As he considers the organization of services, it is necessary that the administrator see and articulate clearly the distinctions between services and programs and agencies. Hospitalization is a service. Vocational rehabilitation, providing many services, is a program. The Bureau of Services for the Handicapped is an agency. It may administer several programs, for example, vocational rehabilitation, services to the blind, disability determinations, and improvement and evaluation of facilities. Programs, in providing services, may pay for the services they provide with appropriations made to them or with the resources of other agencies or individuals.

Services and benefits often are made available to large groups of people on the basis of simple criteria. For instance, SSI benefits are available to all families whose incomes are below a certain level. All citizens over 65 years of age are eligible for Medicare. Elementary and secondary education are for all people within certain age limits.

On the other hand, certain benefits are available on the basis of unique characteristics of the individual. For instance, vocational rehabilitation services are available only to disabled youth and adults. Social Security disability benefits are available only to individuals previously employed who are not capable of any gainful employment, and their children in certain cases.

People eligible for services on a categorical basis (disability) do not lose their eligibility for other benefits available on a more general basis. For instance, an older citizen does not lose his OASI benefits because he accepts a service available under the Older Americans Act. Likewise, a vocational rehabilitation client does not give up his right to education services from the public schools because he accepts training from the VR agency. Benefits under the categorical programs are expected, not to replace general benefits, but to provide for the "extra" needs of those who suffer categorical disadvantage.

Authority of the categorical agencies to provide benefits or services frequently overlaps the authority of a general agency to provide a similar or identical service. For instance, elective surgery may be provided by a rehabilitation agency as a rehabilitation service aimed to restore the individual's ability to work; or it may be provided by Medicaid on the grounds that it will restore the health of an individual who is medically indigent.

# **Overlapping Authority**

This overlapping authority is of concern to administrators who like neat organization charts and clear lines of authority. They tend, at first, to feel that the categorical agency is the usurper and that the function of the general agency should be broad enough to enable it to meet all the needs of the general population it serves. Thus, all health services should be provided by the general health agency, all education by the education agency, all income maintenance and social services by the welfare agency, etc.

Some would go further. Not only would they concentrate programs with similar objectives in one agency, but they would amalgamate the services, washing out the distinction, for instance, between vocational rehabilitation services to an individual and family services to a family.

One may understand the theory of such proposals, while denying their applicability to the unique problems of the categorically disadvantaged. History seems to have demonstrated that intensity and quality of services tend to a common denominator, and that individuals with particularly acute problems get lost in the effort to provide for the masses. Without categorical approaches, few would argue that the blind, deaf and mentally retarded, for instance, would be as well off as they are. Likewise, without the categorical agency, vocational rehabilitation in this case, few would argue that so much progress could have been made in assuring equality of opportunity to disabled people in general.

The functions of the categorical agencies are reasonably the same. They include case identification, diagnosis and evaluation, counseling and guidance, individual plan development, service development, opportunity development and advocacy. In addition to the extent their resources permit, and acting in terms of agreements with the general agencies, they pay for the services their clients receive.

As related to services for disabled people there are at least three ways payments for services needed by a disadvantaged individual may be made. Cash payments or letters of credit may be made

to the individual who will purchase the services he needs wherever he finds it. Veterans educational benefits and supplementary food benefits (food stamps) are handled this way. Services may be paid for by the general agency responsible. For instance, Medicaid pays the bills for medical services of those declared eligible for such benefits. A third way is to appropriate funds directly to the categorical agency which, under its own regulations, will pay for the services provided its clients. There may be, of course, various combinations of these methods.

The categorical agency must, of course, be financed directly to provide the services that are uniquely its to provide. Some of these have been listed above. In addition, it must have additional funding sufficient that its resources are attractive to the functional agency, but the categorical agency need not expect, or be expected to, pay for all the services its clients need.

#### **Medical Services**

An illustration is to be found in the provision of medical services to VR clients. The rehabilitation agency, performing with its own financial resources its unique functions listed in this paper, could be given a letter of credit from the medical service agency. The rehabilitation agency would supervise the provision of all the medical services needed by its clients, along with other services, to assure a unified approach to meeting the needs of the individual, and the bills for the medical services would be paid by the medical agency, just as it pays bills for those whose medical services are not managed by the rehabilitation agency. Funds appropriated to the rehabilitation agency for medical services would be used for "gap filling", that is, paying for the things that the medical agency can't pay for. There probably will always be plenty of these.

This arrangement would assure a unified rehabilitation program for disabled people managed by the agencies whose sole concern is disability. At the same time, it would centralize the payment for most medical services in the medical agency. This would relieve the concern of those who see overlapping authority and duplication of effort in the current situation.

Probably just as important, this will enable the categorical agency (rehab in this case) to concentrate upon the functional limitations of its clients, both those that are attributed to the individual himself and those that result from a hostile or indifferent environment. This is an area of expertness that the rehabilitation agency should continue to develop.

# Severe Disability

In the course of the discussions which produced this document, references were made frequently to "severe" disability, and there was a temptation to attempt to develop a definition of this term. Seminar participants recognized that the clarification of concepts of severe disability is badly needed, but did not feel they had the time or resources to address this subject in the seminar. It is hoped that this report will be a useful tool in pursuing this effort, and some inferences in the report relative to severe disability may be pertinent.

1. It would be a fallacy to assume that severe disability can be defined solely on the basis of categories of impairments such as blindness, deafness, retardation, paralysis, etc. Although one would not want to make an issue over whether a paraplegic, for instance, is severely disabled, some paraplegics, even though their impairments appear to be identical, are much more disabled than others, and many paraplegics do not consider themselves to be severely disabled. The same may be said in connection with individuals with almost any kind of impairment.

- 2. With respect to any class of impairment, it would be unrealistic to attempt to establish a cut-off point and conclude that all on one side of the point are severely disabled and all on the other side, while impaired and even disabled, are not severely disabled. If the range of disability can be thought of as a line, it must be recognized that the number of points along the line are infinite. No two individuals are disabled to precisely the same degree. Present knowledge does not now, and probably never will, justify the fine distinctions required for establishing a cut-off point to distinguish the severely disabled from other disabled persons. It is possible, of course, with present gross measurements, to determine that some individuals are more severely disabled than others, or appear to be so.
- 3. It is clear that severe disability should be defined, if it is to be defined, on the basis of functional limitations; that is, on the basis of the restrictions on normal activity the disability imposes. The greater the restrictions, the more severe the disability.
- 4. On measuring functional limitations, it would be a fallacy not to take into account internal and external factors associated with the individual's impairment. Among the internal factors to be considered will be education, family relationships, cultural level, social acceptance, etc. The external factors are those associated with the impaired person's environment and will include both physical and attitudinal barriers, including the availability of suitable work.

If what has been said about defining severe disability up to this point has seemed negative, it is not because the seminar participants felt negative about efforts to define severe disability. They did want to point out, however, some of the errors frequently made in the effort to develop a definition and some of the difficulties that will be encountered by those who undertake the definitive task.

Actually, a great deal of progress has been made in the number of settings in developing and applying scales for assessing the degree of functional limitation imposed by various impairments and for measuring progress made in treatment. This work should be intensified and extended into all areas of impairment. It is unfortunate that very little of this research has concentrated on how cultural and environmental factors contribute to functional limitation. One of the more significant recommendations in this report is that much more rehabilitation research must be devoted to this area.

Finally, seminar participants feel that a seminar devoted solely to the topic "Severe Disability" would be very profitable at this time and hope the National Rehabilitation Association will take immediate steps to organize and conduct such an effort.







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